



**Arizona Department of Health Services  
Office for Children with Special Health Care Needs  
Integrated Services Grant**



**ISG – Parent Action Council  
July 13, 2006  
Meeting Minutes**

**Attendees:** Barbara Bower, Linda Hamman, Gretchen Jacobs, Twila Pochoema, Ramona Quihuiz, Linda Strayer, Mark Trombino

MEETING ITEM	SPEAKER	DISCUSSION	ACTION ITEMS
<b>Pre-meeting notes</b>		<p>The ISG Parent Action Council met on July 13, 2006 for their summer quarterly meeting. This meeting was a decision-making meeting in regards to the following:</p> <ul style="list-style-type: none"> <li>*ISG PAC Hospital Grievance Project (defining)</li> <li>*ISG PAC Family Profile; (review/edit and advise)</li> <li>*ISG Cultural Competency Community Survey; (review/edit and concur/dissent)</li> <li>*the Medical Home Screening Instruments packet recommended to the ISG Task Force from the ISG QI Clinical Committee; (review, concur/dissent), and</li> <li>*GAPS Questionnaires (Guidance for Adolescent Preventive Services) (review, concur/dissent)</li> </ul>	*Visit <a href="http://www.azis.gov">www.azis.gov</a> website for all current ISG Task Force and Committee information.
<b>Welcome and Introductions</b>	Linda Hamman, ADHS-OCSHCN	<p>Linda Hamman, Health Program Manager III for ADHS-OCSHCN welcomed all the ISG Parent Action Council members to the meeting. Twila Pochoema from the Hopi Nation joined the meeting via conference calling.</p> <p>There were no new attendees at this meeting and the ISG PAC members are all familiar with each other, therefore, no formal introductions took place.</p>	
<b>Announcements</b>	Linda Hamman	The ISG Parent Action Council has been invited to attend the July 25, 2006 meeting of the ISG Quality Improvement (QI) Clinical Committee, if they so desire.	

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<b>Announcements (con't)</b>	Linda Hamman	<p>Additionally, with Marta Urbina leaving ADHS-OCSHCN, a bit of a restructure of the committee has been done. The ISG Parent Action Council will have co-chairpersons and we are pleased that Ms. Barbara Bower and Mr. Mark Trombino have stepped up to volunteer for that. Ms. Linda Strayer has volunteered to be the “nag”, to keep us all on point with appointments and communications. And I will be your support.</p> <p>We want to get some work done in here. We don’t want this to be just about process. Some work will have to be done outside the meeting times. The quarterly meetings should lean more towards reporting of what we are working on and areas of concern.</p> <p>ISG PAC is a review mechanism for the IS Grant. Reviewing everything that is produced by other committees, etc. So we will have documents coming to us at any given time. I will try to send these through the mail so you have time to review before initiating a meeting or conference call. If we do the review work outside the committee meeting, we can come to the meetings with the recommendations (or consensus) we would like to move forward with.</p>	*Structure of ISG PAC Committee will be to have co-chairs; Ms. Barbara Bower and Mr. Mark Trombino.
<b>Handouts</b>		<p><u>The 7-13-06 ISG PAC Meeting Handouts were as follows:</u></p> <ul style="list-style-type: none"> <li>*Agenda</li> <li>*4-13-06 Meeting Minutes</li> <li>*ISG PAC Family Profile</li> <li>*ISG Cultural Competency Community Survey</li> <li>*Medical Home Screening Instruments Packet</li> <li>*GAPS Questionnaires (Guidance for Adolescent Preventive Services)</li> <li>*ISG PAC Action Matrix updated 7-11-06</li> <li>*ISG Project Abstract Form</li> <li>*CRS Grievance Policy</li> <li>*ISG PAC Hospital Grievance Project NET Resource Listing</li> <li>*ISG Links to Partners Website Listing</li> <li>*ISG PAC Action Items from Minutes Report (all meetings)</li> <li>*ISG Year One Progress 2005-2006/Purpose, Goals, Tasks</li> <li>*Emergency Room Task Force Notice from ADHS</li> <li>*Education/Training Tracking Form (PAC-specific form)</li> <li>*Evaluations</li> </ul>	

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	Mark Trombino	Raised the question if the new ADHS Emergency Room Task Force was for special needs. Ms. Hamman explained that it was all encompassing whereby the ER Task Force is looking at how fast you get to the ER and what happens when you get there. What would be a good idea is if someone from the Council joined the Task Force, whereby they could bring those issues to the table.	*Is ADHS ER Task Force addressing special needs?
	Linda Strayer	As one of our goals is to report on what is going on with our communities and how parents are involved; how do you want that reported and to whom?  Ms. Hamman clarified that the reporting of activities and such would be made to her.	*Reporting on community activities, parental involvement, etc. will be made to Linda Hamman.
Review/Trainings	Linda Hamman	What are the trainings that are taking place or that you are attending? I believe a Training Log was sent out to everyone but I will send it out again.  Ms. Strayer reminded the group of the upcoming training conference.	*Linda H. to send out the Training Log to the members. A Training Conference is pending.
Review/4-13-06 Meeting Minutes	Linda Hamman	Please provide any comments or clarification on the minutes.  The ISG PAC reviewed the minutes and accepted them without corrections.	*ISG PAC accepted the 4-13-06 meeting minutes without corrections.
Review/ISG PAC Family Profile	Linda Hamman	Is there anything to change on the Family Profile? We had been finalizing this from the 4-13-06 meeting and had worked on it with the conference calls.  The group added some text to the Family Profile. Also made some typographical and formatting changes. There was a brief discussion on if the therapy or services provided in school settings should be listed. The group suggested that any school information could be listed under the #2 section line item of "Other services/supports you want to mention".  The ISG PAC gave consensus that the Family Profile could go to other ISG Committees for review and comment.	*Profile to be used for parents to fill out *ISG PAC consensus for Family Profile (draft) to go to other ISG Committees for review and feedback.
	Linda Hamman	One of the surveys the Parent Leaders use is the Family Satisfaction Survey, and it includes similar questions as the surveys we are reviewing today. A concern I had is that if we are asking all these life questions to families along with service questions, (are you getting services, are you pleased with services, etc.); is it really improving quality of life as a family. Is it helping the family to achieve the outcomes they wish to achieve?	*Are the surveys helping families to achieve the outcomes they wish to achieve?

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<b>Review/ISG Cultural Competency Community Survey; ISG QI Clinical's TF Recommendation packet of Medical Home Screening Instruments; and the GAPS Questionnaires</b>	Linda Hamman	<p>We have some documents to review from various ISG Committees. The Community Survey comes from the ISG Cultural Competency Committee. The Medical Home Screening Instruments packet is from the ISG QI Clinical's May 2006 Task Force recommendations. And the GAPS Questionnaires (Guidance to Preventive Adolescent Services) comes from the ISG Adolescent Health Community Advisory Group. Please take a moment for review and we can then comment when you are done. The group took time for their review.</p> <p><u>Please see attached documentation that outlines the feedback from the ISG Parent Action Council on:</u></p> <ul style="list-style-type: none"> <li>*ISG Cultural Competency Committee's Community Survey</li> <li>*GAPS Questionnaires (Guidance for Adolescent Preventive Services Questionnaires)</li> <li>*ISG QI Clinical Committee's May 2006 Task Force Recommendation of the Medical Home Screening Instruments</li> </ul> <p><i>Contained within this packet were the screening tools of:</i></p> <ul style="list-style-type: none"> <li>-The Children with Special Health Care Needs (CSHCN) Screener</li> <li>-PEDS (Parents' Evaluation of Developmental Status)</li> <li>-M-CHAT (Modified Checklist for Autism)</li> <li>-PSC (Pediatric Symptom Checklist)</li> <li>-CRAFFT (14-18 year old self-report on substance abuse)</li> <li>-Dental Screen from the Association of State and Territorial Dental Directors</li> </ul>	<p>*See final page of minutes for ISG PAC feedback on all topics/documents for review</p>
	Group discussion	<p>As the ISG PAC reviewed and discussed the documents, some observations were as follows:</p> <ul style="list-style-type: none"> <li>-PEDS-like test is on the Internet, whereby, nothing like that was ever on the Internet before. Parents can answer the questions and get a score. It was agreed that the parents should still see a doctor and verify.</li> <li>-The word autism is still a bit scary for parents to hear. By the mere fact that the provider is initiating some of the tools to the parents or child, are we alarming parents? Will they automatically think something is wrong with their child because the provider wants to administer these tools and/or questionnaires? On the other hand, it was also observed that disbursing the information may get the parents thinking in the direction they need to think.</li> </ul>	<p>*Internet now has "testing" resources for autism. Parents take test via Internet and get scores. Is it reliable? Still need a doctor.</p> <p>*Autism is still an alarming word to use</p> <p>*If a care coordinator is used, do the outcomes improve for</p>

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		<p>-Do the outcomes for children and families improve if a care coordinator is stationed at the care facility and coordinates the services?</p> <p>-Some providers are taking the lead and using screening tools already in their practices.</p> <p>-New disability screening tool is out for age 3 that centers around if the child is disabled but not showing any defined symptoms.</p>	<p>the family and the child?</p> <p>*Screening tools are being initiated by existing providers</p> <p>*New disability screening tool for age 3. Disabled but not showing? Does this tool have a name?</p>
	Linda Hamman	<p>All the tools will help us. They help ask the question of what are those things you would normally be doing for a child 0 to 3; and then further determine, what is or where is, the child functioning behind in. It is up to us to find this so we can direct the services better. By determining if they are functioning behind and what area it is, we are better able to catch it in early stages. We can also find out if a child is functioning at the level that services are needed. Do they need early intervention? Can we assess them that they need the chronic-on going services?</p>	
<b>Hospital Grievance Project</b>	Group discussion	<p>The ISG PAC discussed the Hospital Grievance Project. They redefined the project (Grievance and Appeal Process Project) to include hospitals, specific programs within state agencies; and insurance companies. This project will help teach parents how to be advocates. If this information is given to the parent, after their emergency or other issue has passed, they can re-address it, but at least they have been provided the information so they can re-address it. Many parents don't even know they can appeal the service they receive in hospitals or through a state program. Hospitals always try to steer the parents away from filing any type of grievance. The hospitals tell them automatically "it's our policy", etc. Well, we want to know what that policy is. And we want to know if the entity changes the policy based on a grievance and/or appeal filed. How do they follow-through and how do they report back to the families.</p> <p>It will help the parents to feel as though they are taking control of their child's care. We can help by getting the information to them. We are, in essence, educating the parents. And policy can be changed. Even if parents do not get anywhere with a specific grievance, remember that they are building a case.</p>	<p>*Redefined Hospital Grievance Project to the Grievance and Appeal Process Project that will encompass hospitals, specific programs within state agencies, and insurance companies.</p> <p>*Ms. Jacobs to bring in document on how to be an advocate.</p>

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<b>Hospital Grievance Project (con't)</b>		<p>The ISG PAC members chose the entities they would research for the project:  <u>Grievance and Appeal Process assignments:</u>  Gretchen Jacobs –AzEIP  ALTCS (AHCCCS Long Term Care System)  Junior League Advocacy Section  Barbara Bower – St. Joseph’s Hospital  Phoenix Children’s Hospital  Linda Strayer - Cigna  Mark Trombino – Aetna</p> <p>The PAC members will obtain the grievance and appeal processes from the specific entities.</p>	<p>*Barb Bower will contact Jim Murray for inclusion into the project  *Possible flyers or brochures to be developed for parents with end results or guidance on how to grieve and appeal if involved with targeted entities.  *What other state agencies can be included?</p>
<b>Update ISG PAC Action Matrix</b>	Group	ISG PAC reviewed the updated copy of the ISG PAC Committee Action Planning Matrix document. The PAC Matrix had been updated with the objectives and activities noted from PAC’s last meeting on 4-13-06.	*Redefinition of the Hospital Grievance Project to the Grievance and Appeal Process Project will be noted within the ISG PAC Action Matrix.
<b>Questions / Discussion; Items from the Floor</b>	Linda Strayer	<p>I would like to invite other parents from the mental health arena to the next conference call and the next ISG Parent Action Council meeting in October. This is in alignment with the Action Matrix.</p> <p>Ms. Hamman noted that a new Sickle Cell team is forming and the parents will be invited from this group too.</p>	<p>*ISG PAC to include parents from mental health arena in conference calls and future meetings.  *ISG PAC to invite Sickle Cell parents to be involved.  *Invite Renaldo Fowler from Arizona Disability Law to 10-12-06 ISG PAC meeting.</p>

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Next Meeting		<p>Next conference call: August 17, 2006 10am-11am  Time change on September conference call?  Linda Strayer asked the PAC how far in advance do you want the reminder? It was consensus that reminders should go out a week prior to the conference call and/or meeting.</p> <p><b>Next ISG PAC Quarterly Meeting</b>  <b>October 12, 2006 11am-2pm, ADHS Bldg., Room 345A</b></p>	<p>*Linda Strayer will send out conference call and meeting reminders one week prior.  *Pam to send Linda Strayer the 2007 Schedule of ISG PAC Meetings  *Pam to send Linda Strayer the listing of project entities chosen and by whom.</p>

### **ISG – PAC Feedback on GAPS**

The ISG Parent Action Council concurs with GAPS as a questionnaire type tool that can be used. The feedback (7-13-06) is as follows:

- Covers a lot of topics which is good but could mean adolescents won't answer because of length.
- Will adolescents answer it – parents will answer the Parent/Guardian but what about teens?
- Administer in a safe environment and give time to complete.
- Not enough space on forms to list medical history and medications of CYSHCN.
- Make sure it stays confidential
- Confidential is in a different font size and location on the questionnaires
- Reading level on the questionnaires is too high
- The font and size is not easily readable
- The questionnaire should be available in alternative formats for different special needs

### **ISG – PAC Feedback on Community Survey**

The ISG Parent Action Council provided feedback (7-13-06) on the ISG Cultural Competency's Community Survey as follows:

- Correlate with AzEIP questionnaire sent to parents (involves a release). AzEIP questionnaire is similar.

- Where will this go?
- What are you trying to accomplish?
- How will it be administered?
- How will results be given back to the community? Results *need* to get back to the community.
- After population has been surveyed, redistribute a thank you back to the surveyed population.
- Do they or will they read and use the information (whoever initiated survey)
- Quantify the results
- Survey will help under-served community needs on reservations

**ISG PAC Feedback on Medical Home Screening Instruments Packet**  
**(QI Clinical's May 2006 Recommendations to the ISG Task Force – inclusion in ISG Care Coordination Study)**

The ISG Parent Action Council concurs with the QI Clinical Committee's Task Force recommendation of the Medical Home Screening Instruments packet. The feedback (7-13-06) is as follows:

- Define the steps of administering the tools.
- Who is going to help administer them?
- What are the logistics of the project (Care Coordination Study <aka Medical Home Project>)?
- How are the tools going to be implemented?
- Need to answer questions without distractions. Safe environment.
- Using word autism is alarming still, may wish to be careful (RE: M-CHAT tool / footnote reference – can we take the footnote off?)
- PAC is pleased that screening tools are becoming more prevalent. Parents need to know that these tools and other resources are available to help them with diagnosis, caring of, and service coordination of their special needs children.